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**OLDER ADULTS' AWARENESS OF COMMUNITY HEALTH  
AND SUPPORT SERVICES FOR DEMENTIA CARE**

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# Older Adults' Awareness of Community Health and Support Services for Dementia Care\*

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## RÉSUMÉ

L'article examine où les personnes âgées peuvent chercher l'aide pour prendre soin d'un parent avec démence et les facteurs associés à leur identification des services de santé et de soutien communautaires comme des sources d'aide. Les auteurs menées des entrevues téléphoniques, à l'aide de numérotation de chiffres aléatoires, de 1,152 adultes âgés de 50 et plus dans la ville de Hamilton. À déterminer les sources de soutien, plus 37 pour cent des répondants a identifié leur médecin, 33 pour cent a identifié un soutien informel comme la famille et voisins et 31 pour cent a identifié des services de santé maison. Seulement 18 pour cent a identifié des services de soutien communautaires. Participants femmes ayant des niveaux plus élevés de scolarité étaient plus susceptibles d'identifier leur médecin comme une source de soutien. Savoir où trouver renseignements sur services de soutien communautaires était associée à une probabilité accrue de mentionnant des médecins et des services de santé maison comme sources d'aide.

## ABSTRACT

The article examines where older adults seek help in caring for a parent with dementia and the factors associated with their identification of community health and support services as sources of assistance. The authors conducted telephone interviews, using random digit dialing, of 1,152 adults aged 50 and over in the city of Hamilton. Respondents received a vignette that raised issues related to parental dementia. In identifying support sources, over 37 per cent of respondents identified their physician, 33 per cent identified informal support such as family and neighbors, and 31 per cent identified home health services. Only 18 per cent identified community support services. Female participants having higher levels of education were more likely to identify their physician as a source of support. Knowing where to find information about community support services was associated with an increased likelihood of mentioning physicians and home health services as sources of assistance.

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Dementia is an increasingly prevalent and important health concern in Canada (Canadian Study of Health and Aging [CSHA] Working Group, 2000) and globally (Wimo, Winblad, Aguero-Torres, & von Strauss, 2003). Most older adults with dementia continue to live in their homes with the support of informal caregivers (CSHA Working Group, 1994). Informal caregivers of persons with dementia experience a significant burden in their roles. Although many communities have an array of community health and support services to assist older adults with dementia and their caregivers, the literature suggests that these services are underutilized and that one of the barriers to their use is the lack of awareness of such services (Strain & Blandford, 2002). The research literature on service awareness has important methodological limitations: in particular, acquiescence bias, whereby respondents over-report their awareness of services. The purpose of this descriptive study is to describe where older adults would turn to for help in response to vignettes or short stories related to caring for a parent with dementia, and the socio-demographic factors associated with their choice of supports. We used vignette methodology to avoid the acquiescence bias so common in service awareness research.

### *Dementia*

It has been estimated that the global prevalence of dementia in 2001 was more than 24 million people aged 60 years or older, a prevalence rate of approximately 3.9 per cent of that age group (Ferri, Prince, Brayne, Brodaty, Fratiglioni, Ganguli et al., 2005). This prevalence is projected to double every 20 years to more than 81 million people by 2040 (Ferri et al., 2005). In North America, the prevalence of dementia among those aged 60 years and older in 2001 was 6.4 per cent (Ferri et al., 2005). The CSHA Working Group (2000) has estimated that there are 60,150 new cases of dementia per year in Canada. Of those older Canadians with dementia, 64 per cent were diagnosed with Alzheimer's disease (AD), 19 per cent with vascular dementia, and 17 per cent with other forms of dementia

(Hill, Forbes, Berthelot, Lindsay, & McDowell, 1996). Dementia has been described as a major burden for health and social care systems (Wimo et al., 2003). The net economic cost of dementia in Canada in 1991 was estimated to be at least CAN \$3.9 billion (Østbye & Crosse, 1994), and it is likely to be much higher now, 17 years later.

Dementia also places a significant burden on informal caregivers. About half of all people with dementia in Canada are living in the community, and more than 98 per cent of them have a caregiver, usually an unpaid family member, relative, or friend (CSHA Working Group, 1994). Caregivers of a family member with dementia are more likely to experience chronic health problems, depression, and social isolation, compared to those caring for cognitively intact elderly (CSHA Working Group, 1994). Given the increasing number of people with dementia, the impact on informal caregivers of providing care, and the preference of older adults to "age in place" (Chappell, McDonald, & Stones, 2008), increasing attention is being focused on strategies to support caregivers in their roles. One such strategy involves the use of support provided by community health and support services.

### *Community Health and Support Services*

Many communities have a broad array of community health and support services available to assist persons with dementia and their caregivers. Such services provide an alternative to institutionalization. Service examples include home health services – such as nursing and homemaking – as well as community support services (CSSs). Community support services, as defined here, are delivered in the home or community to assist people with health or social problems to maintain the highest possible level of social functioning and quality of life. Examples of CSSs are (a) adult day programs, (b) volunteer visiting, (c) caregiver support programs, (d) food services, (e) transportation services, and (f) organizations such as the Alzheimer Society. Access to CSSs is particularly challenging because of the multiplicity

of small agencies providing these services, the lack of a central access point, and the lack of awareness of such services. Further, the complexity of the health and social support system makes it challenging for older persons, their families, and health care professionals to navigate the system.

There is some evidence that use of community-based services has positive benefits for frail elders (with and without dementia) and their caregivers (Zarit, Gaugler, & Jarrott, 1999). In their review of the literature, Zarit et al. (1999) found that such services resulted in lower levels of care-related stressors, perceived burden, depression, and anger. At the same time, patients with dementia experienced improved life satisfaction and mood, engagement in activities, and fewer behavioral difficulties. In a qualitative study of family caregivers of relatives with AD or a related disorder, community services were found to provide benefits including the experience of community and support, a gain in knowledge, receipt of personal renewal, and benefits to the patient (Winslow, 2003).

### *Literature Review*

Underutilization of community-based services – that is, the gap between expressed need and service use – has been recognized as a general problem in the field of aging (Strain & Blandford, 2002) and a particular problem in dementia care (Brodaty, Thomson, Thompson, & Fine, 2005; Buono, Busato, Mazzetto, Paccagnella, Aleotti, Zanetti et al., 1999; CSHA Working Group, 1994; Collins, Stommel, Given, & King, 1991; Forbes, Morgan, & Janzen, 2006; Vetter, Steiner, Kraus, Moises, Kropp, Moller et al., 1998). Research has suggested that community health and support services are underused, largely due to lack of awareness or knowledge of such services (Strain & Blandford, 2002; Vetter et al., 1998). Krout (1983) distinguished between awareness and knowledge of services. Awareness is a general understanding that a service exists. Knowledge involves “knowledge of what the program is or does, where it is located, or how one gets involved with it” (Krout, 1983, p. 155). Most of the following research addresses awareness, not knowledge, of services.

Strain and Blandford (2002), in the Manitoba Study of Health and Aging, studied the awareness and use of community-based services among 293 older person-caregiver dyads (44% with cognitive impairment). While they found few people unaware of home-delivered meals (7.9%), in-home nursing (9.5%), personal care (10.6%), and homemaking (11.2%), a much larger proportion was unaware of hospital respite (49.5%), nursing home respite (47.4%), in-home respite (43.8%), day hospitals (43.3%), and day centres (35.7%). For these latter services

(i.e., day centres, day hospitals, in-home respite, nursing home respite), the second most common reason given for non-use was that caregivers were not aware of the service. In that study, researchers provided participants with the categories of available community services.

Studies of persons with dementia and their caregivers have also demonstrated limited awareness and utilization of community health and support services (Brodaty et al., 2005; Buono et al., 1999; Caserta, Lund, Wright, & Redburn, 1987; Collins et al., 1991; Maslow, 1990; Vetter et al., 1998). For example, Collins et al. (1991) found that among caregivers of persons with AD not using specific services, the percentage who were not aware of availability of services varied by service as follows: (a) support group (10%), (b) visiting nurse (18%), (c) home-delivered meals (20%), (d) transportation service (30%), (e) counseling (36%), (f) day respite program (39%), and (g) temporary overnight care (58%). Another study found that the main reason reported for non-use of services (e.g., counseling, support groups, Meals on Wheels, and adult day care) was that over 60 per cent of caregivers of persons with AD ( $n = 36$ ) were unaware of the availability of such services (Vetter et al., 1998). A third study found that 36 per cent of caregivers of dementia patients ( $n = 597$ ) did not know whether community services were available or not (Caserta et al., 1987).

Some research has been conducted on the factors associated with utilization of CSSs for dementia care (Brodaty et al., 2005; Caserta et al., 1987; Strain & Blandford, 2002; Vetter et al., 1998), but relatively little on the factors associated with awareness of such services. Collins et al. (1991), in their study of family caregivers of patients with AD, found that older caregivers were more likely to be uncertain about the availability of services, and that caregiver depression was associated with less knowledge of service availability. Our review of the factors associated with, or assessed for their association with, the use of CSSs for dementia care in the research literature guided our selection of the variables in this study. Specifically, researchers have found that socio-economic variables (i.e., employment, income, education) (Collins et al., 1991; Cox, 1999; Ortiz & Fitten, 2000), demographic variables (i.e., age, sex) (Collins et al., 1991; Robinson, Buckwalter, & Reed, 2005), and social variables (i.e., social support, social networks) (Caserta et al., 1987; Cotrell & Engel, 1998) are associated with the use of dementia care services. To date, little evidence exists of associations between the use of dementia care services and other variables such as language and disability (Brodaty et al., 2005; Ortiz & Fitten, 2000).

There is limited Canadian information on older persons' awareness of community health and support



services for situations of parental dementia and the factors associated with such awareness. Instead, the literature has focused on use, availability, and acceptability of services, and barriers to their use (Forbes, Markle-Reid, Hawranik, Peacock, Kingston, Morgan et al., 2008; Jansen, Forbes, Markle-Reid, Hawranik, Kingston, Peacock et al., 2009; Strain & Blandford, 2002). For example, a qualitative study exploring the use and satisfaction with home and community-based services for persons with dementia from the perspective of family caregivers found that issues of availability and acceptability captured caregivers' experiences (Forbes et al., 2008). Caregivers talked about the need for a continuum of home and community-based services and concerns such as inconsistency of care provider, inflexible care, and cost of services.

In addition to the limited research on factors associated with awareness of community-based services, there are important methodological limitations of the service awareness literature, including the literature related to dementia care services. In most studies, respondents have been provided with lists of service or agency names and asked to indicate whether or not they were aware of or using each one (Buono et al., 1999; Caserta et al., 1987; Collins et al., 1991; Strain & Blandford, 2002; Vetter et al., 1998). This methodology leads to acquiescence bias, the tendency of respondents to answer the question positively regardless of the content (Calsyn & Winter, 1999). In several studies, Calsyn, Roades, and Calsyn (1992) provided older adults with a fictitious service or agency name and found that 20–30 per cent of respondents reported familiarity with that service. One approach to address acquiescence bias in studies of service awareness is to use open-ended questions to solicit the name or types of agencies, but this approach has seldom been used in studies of service awareness.

The purpose of this study is to measure older persons' awareness of community health and support services when presented with a scenario related to caring for a parent with dementia. We were also interested in the socio-demographic and other factors, including caregiving status, associated with older adults' identification of community health and support services as sources of help in caring for a parent with dementia. We expected that caregivers might have greater awareness of community health and support services than non-caregivers, as research has found that most caregivers have a viable informal network of secondary supports that may help address barriers to the use of formal services (Cotrell & Engel, 1998).

Our study addressed the following research questions:

1. Where would older adults turn for assistance when faced with a scenario related to caring for a parent with dementia?
2. What factors are associated with the identification of community health and support services as a source of assistance in caring for a parent with dementia?
3. Do caregivers have greater awareness of community health and support services than non-caregivers?

## Method

The study design was a cross-sectional descriptive survey, best used to obtain a description of a phenomenon (de Vaus, 2002). Although this study design can establish association between variables, it cannot determine causation (Streiner & Norman, 1998). The study involved a telephone survey of adults aged 50 years and older residing in the city of Hamilton, Ontario, Canada. Study methods have been described previously (Denton, Ploeg, Tindale, Hutchison, Brazil, Akhtar-Danesh et al., 2008) and are summarized here.

### Study Setting

Hamilton, Ontario, is Canada's ninth largest city with a population of nearly 700,000 (Statistics Canada, 2006a). In 2006, Hamilton had a higher percentage (15.1%) of adults aged 65 years and older compared to Canada (13.7%) as a whole (Statistics Canada, 2006b). Hamilton has an array of community health and support service agencies available for persons with dementia and their caregivers.

### Vignette Methodology

We used a vignette methodology to address the issue of acquiescence bias in the literature. The use of vignettes or short stories is an established research methodology (Hughes & Huby, 2002; Schoenberg & Ravdal, 2000; Spalding & Phillips, 2007). Vignettes are short descriptions of hypothetical situations that closely approximate real-life decision-making situations. Respondents are read the vignettes and asked to respond to the hypothetical situations. Advantages of vignettes are that they are interesting to the respondents, they provide context, and they can be used to address sensitive topics such as health care (Hughes & Huby, 2002). In the case of research related to awareness of community health and support services, the use of vignettes helps to avoid acquiescence bias, in which lists of services are presented to respondents, and investigator bias, whereby the list of services is bounded by the investigators' awareness of available services.

The vignettes used in this study were developed by front-line service providers to represent realistic and familiar situations faced by older adults for which community health and support services would be appropriate; thus, they have high face and content validity. The vignettes were pretested and some modifications were made.

### Data Collection

Awareness of community health and support services was measured through a telephone survey of older adults. A survey firm was contracted to complete the interviews using a Computer Assisted Dialing Information (CADI) system. Interviews were completed within a six-week period beginning mid-February 2006. English-speaking residents aged 50 years of age and older were invited to participate in the study. The sample was obtained by randomly selecting telephone numbers from a list of telephone numbers for all residents of Hamilton.

Each participant was read four short vignettes. Participants were asked, "If you were in this situation, what would you do?" and prompted with "Anything else?" up to four times, in order to establish multiple sources of assistance. We then asked, "Can you name an organization or program in our community that you would turn to in that situation?" and used up to four prompts until a CSS was named. We also collected demographic, economic, health, and social information about participants. Participants were asked if they had provided any unpaid care or assistance to one or more seniors in the past 12 months. If required, the following probes were provided as examples of caregiving: visiting seniors; helping them with shopping, banking, personal care (bathing, assisting with dressing); and taking medications. If participants indicated they had provided care, they were considered as caregivers for the purpose of this analysis. The study received ethics approval from McMaster University Research Ethics Board.

### Sample Size

Sample size calculation was described in an earlier paper (Denton et al., 2008). Of the total 12 vignettes used in the 2008 study, three vignettes addressed issues of caring for a parent with dementia (see Table 1), and the responses to these vignettes are reported in this paper. A sample size of 384 was needed for each vignette. The 12 vignettes were divided into three groups (panels) containing four vignettes; a vignette related to caring for a parent with dementia was included in each group of four vignettes. The total sample size was  $3 \times 384 = 1,152$ . Thus, 384 older adults responded to each vignette, with 1,152 participants responding in total.

### Data Analysis

Interviewers entered participants' responses to the vignettes as verbatim responses. These responses were coded and recoded by the survey firm's coders, working collaboratively with the research team, into 150 initial categories and then into 20 meaningful cate-

**Table 1: Vignettes**

| Vignette Number | Panel | Vignettes  |
|-----------------|-------|--|
| 1               | A     | You are the main caregiver for your parent who has Alzheimer's disease. You have discovered that your mother has been taking more pills than she should.   |
| 2               | B     | You are an only child of a parent with Alzheimer's disease. For years you have been bringing him meals, doing his laundry, and paying his bills. Your spouse is sick, and now you have to help him/her, too. You are feeling overwhelmed and frustrated. |
| 3               | C     | Your mother, who lives with you, is very confused and can't be left alone. You want to keep her at home, but you have to go to work. The rest of the family are working and cannot help.   |

gories for the purpose of analysis (see Table 2). We had several rounds of peer checking with community partners to ensure that the reduction from 150 to 20 categories was accurate and appropriate. The survey firm provided an Statistical Package for the Social Sciences (SPSS) file of the data to the researchers.

Age was measured as a categorical variable (age 50–60, age 61–70, and 71 and older, with age 50–60 as the reference category). Sex was measured as 1 for females and 0 for males (reference category). Marital status was measured as a categorical variable but was recoded to 1 = married and 0 = not married (reference category) for the purpose of the regression analysis. Four levels of education were measured: (a) less than high school (reference category), (b) some high school or graduated from high school, (c) other post-secondary education including community college and apprenticeship to the trades, and (d) university or higher education. Income was measured in four categories. Being foreign born was measured as 1 = yes and 0 = born in Canada (reference category). Self-rated health was measured as a categorical variable (excellent or very good as the reference category; good, and fair or poor). The respondent's functional health was measured as having a limitation at home or outside the home (1 = yes, 0 = no as the reference category). Membership in clubs or voluntary organizations such as seniors centres, church, or social groups was measured as 1 = member and 0 = non-member (reference category). Caregiving status was measured as 1 = caregiver for a senior in the past year and 0 = non-caregiver (reference category). Participants were asked



**Table 2: Categories of participant responses to vignettes**

1. Community support services
2. Spouse
3. Son/daughter
4. Friends and neighbours
5. Relatives
6. Physician
7. Emergency
8. Clinics/hospitals
9. Other health professionals
10. Non-health professionals
11. Pastor/clergy/faith community
12. Social and recreation services
13. Nothing
14. Home health services
15. Long-term care/residential care
16. Self-help/personal strategy
17. Government
18. Information and referral sources
19. Disease-specific agencies
20. Community Care Access Centre

**Note. For the purpose of this analysis:**

**Informal supports included spouse, son/daughter, friends, neighbours, relatives, and self-help strategies**

**Home health services included home health services and Community Care Access Centre**

**Community support services included 37 agencies such as adult day programs, Alzheimer Society, transportation services, and Meals on Wheels**

where they would find information about CSSs with three opportunities to respond. The number of sources of information was summed and ranged from 0 to 3.

To answer the first question, "Where would older adults turn for assistance when faced with a scenario related to caring for a parent with dementia?", we focused on the five most frequent responses given by respondents: (a) informal sources including family, friends, and neighbours as well as self-help strategies; (b) home health services (including the Community Care Access Centre [CCAC] which is a one-stop access centre for home health services covered under the Ontario Health Insurance Plan); (c) CSSs; (d) long-term or institutional care; and (e) their physician. These responses were given by 81.3 per cent of participants as their first response.

To answer the second question, "What factors are associated with the identification of community health and support services as a source of assistance in caring for a parent with dementia?", we used logistic regression, as the identification was measured as a dichotomous variable. We included the following variables in the regression analysis: age, sex, education, country of birth, self-rated health, marital status, membership in clubs or organizations, and functional limitations of the care recipient. The inclusion of caregiver status as a variable

in the regression analysis permitted us to address the third question: "Do caregivers have greater awareness of community health and support services than non-caregivers?" Using logistic regression, we regressed the identification of services on the variables just identified.

Odds ratios are presented. An odds ratio greater than 1.0 indicates an increased likelihood of identification of services; a 95 per cent confidence interval of an odds ratio that does not include 1.0 indicates a statistically significant result.

## Results

### Participants

A total of 22,072 different telephone numbers in Hamilton were called, and 15,857 households were contacted. We were unable to contact 6,215 households because either the number was not in service, the line was busy, an answering machine took the call, or there was no answer. Of the 15,857 households contacted, 10,373 had a resident aged 50 years or older. Following exclusion of 1,034 households due to language barriers and illness, and 8,180 refusals, we conducted 1,159 interviews; seven of these were removed from the database due to incomplete data, leaving 1,152 usable interviews, for a response rate of 12.4 per cent (1,159/9,339) of eligible households.

Participants represented a wide cross-section of older adults living in Hamilton. The demographic profile of the sample is described in Table 3. Over two thirds of participants were female and most were married (63%), over the age of 60 (57%), and born in Canada (71%). Almost half had high school education or less (47%), and 28 per cent had university education. Household income varied with the most frequent category being CAN \$60,000 or more (39%). A high proportion reported excellent, good, or very good self-rated health (54%), and most reported no functional limitations (60%). A high proportion (56%) reported two or more information sources. A comparison of our sample to Hamilton data from the 2006 and 2001 Census of Population was presented earlier (Denton et al., 2008). Our sample included a higher proportion of females, people who were Canadian born, and people with incomes higher than the Hamilton population had (Denton et al., 2008).

Analysis was conducted on the full sample ( $n = 1,152$ ) instead of the three separate groups responding to each vignette. To ensure that the three groups were not significantly different on demographic variables, a chi-square test was conducted to compare each demographic variable between the three groups. No significant differences were found between groups on any of the demographic variables (education, sex, marital

**Table 3: Demographic description of participants**

| Demographic Variable                                   | Total Sample<br>( <i>n</i> = 1,152) % | Caregivers<br>( <i>n</i> = 474) % | Non-Caregivers<br>( <i>n</i> = 678) % | Chi Square                                |
|--|---------------------------------------|-----------------------------------|---------------------------------------|---|
| <b>Age*</b>  |                                       |                                   |                                       |   |
| 50–60  | 42.6                                  | 49.2                              | 38.1                                  | $\chi^2 (2, n = 1,152) = 23.1, p = 0.000$ |
| 61–70  | 29.5                                  | 30.2                              | 29.1                                  |   |
| 71+  | 27.9                                  | 20.7                              | 32.9                                  |   |
| <b>Gender</b>  |                                       |                                   |                                       |   |
| Male   | 28.7                                  | 26.8                              | 30.1                                  | $\chi^2 (1, n = 1,152) = 1.5, p = 0.224$  |
| Female   | 71.3                                  | 73.2                              | 69.9                                  |   |
| <b>Education*</b>                                      |                                       |                                   |                                       |   |
| Less than high school                                  | 5.0                                   | 2.3                               | 6.9                                   | $\chi^2 (3, n = 1,142) = 18.9, p = 0.000$ |
| Some or all of high school                             | 41.9                                  | 39.1                              | 44.0                                  |   |
| Community college non-university<br>certificate, trade | 25.4                                  | 26.5                              | 24.6                                  |   |
| University or higher                                   | 27.7                                  | 32.1                              | 24.6                                  |   |
| <b>Country of Birth</b>                                |                                       |                                   |                                       |   |
| Born in Canada   | 71.4                                  | 72.4                              | 70.6                                  | $\chi^2 (1, n = 1,142) = 0.4, p = 0.529$  |
| Foreign born   | 27.8                                  | 26.8                              | 28.5                                  |   |
| <b>Language</b>  |                                       |                                   |                                       |   |
| English  | 94.6                                  | 95.4                              | 94.1                                  | $\chi^2 (2, n = 1,152) = 1.0, p = 0.593$  |
| French   | 0.6                                   | 0.6                               | 0.6                                   |   |
| Other  | 4.8                                   | 4.0                               | 5.3                                   |   |
| <b>Marital Status</b>                                  |                                       |                                   |                                       |   |
| Married, common law                                    | 63.1                                  | 67.2                              | 60.2                                  | $\chi^2 (3, n = 1,151) = 7.1, p = 0.068$  |
| Widowed  | 19.2                                  | 16.5                              | 21.1                                  |   |
| Divorced, separated                                    | 11.6                                  | 9.9                               | 12.7                                  |   |
| Single, never married                                  | 6.5                                   | 6.3                               | 6.0                                   |   |
| <b>Household Income (\$)†</b>                          |                                       |                                   |                                       |   |
| \$20, 000 or less                                      | 15.0                                  | 9.6                               | 18.8                                  | $\chi^2 (4, n = 912) = 24.9, p = 0.000$   |
| \$20, 001–\$40, 000                                    | 27.6                                  | 25.5                              | 29.1                                  |   |
| \$40, 001–\$60, 000                                    | 18.6                                  | 18.4                              | 18.8                                  |   |
| \$60, 001–\$80, 000                                    | 16.7                                  | 21.3                              | 13.4                                  |   |
| \$80,001+  | 22.0                                  | 25.3                              | 19.8                                  |   |
| <b>Self-Reported Health*</b>                           |                                       |                                   |                                       |   |
| Excellent, very good                                   | 54.5                                  | 60.7                              | 50.1                                  | $\chi^2 (2, n = 1,147) = 13.5, p = 0.001$ |
| Good   | 28.2                                  | 25.6                              | 30.1                                  |   |
| Fair, poor   | 17.3                                  | 13.7                              | 19.7                                  |   |
| <b>Functional Limitations*</b>                         |                                       |                                   |                                       |   |
| No   | 60.2                                  | 66.7                              | 55.9                                  | $\chi^2 (1, n = 1,137) = 12.6, p = 0.000$ |
| Yes  | 39.8                                  | 33.6                              | 44.1                                  |   |
| <b>Number of Information Sources*</b>                  |                                       |                                   |                                       |   |
| 0  | 13.8                                  | 9.5                               | 16.8                                  | $\chi^2 (3, n = 1,152) = 31.6, p = 0.000$ |
| 1  | 29.8                                  | 26.8                              | 31.9                                  |   |
| 2  | 30.6                                  | 30.2                              | 30.8                                  |   |
| 3  | 25.9                                  | 33.5                              | 20.5                                  |   |

Number of study respondents vary across independent variables due to missing data.

\* Significant difference found between caregiver and non-caregiver groups.

† The number of study responses to the household income question was: 376 (caregiver), 536 (non-caregiver), 912 (both males and females) respectively.

status, language, country of birth, health) except age:  $\chi^2 (4, n = 1,152) = 11.2, p = 0.03$ . Based on these findings, our groups were similar enough to combine into one group for analysis.

Of the total sample of 1,152 respondents, 474 (41%) identified themselves as having provided care to a senior in the previous 12 months. A chi-square test was

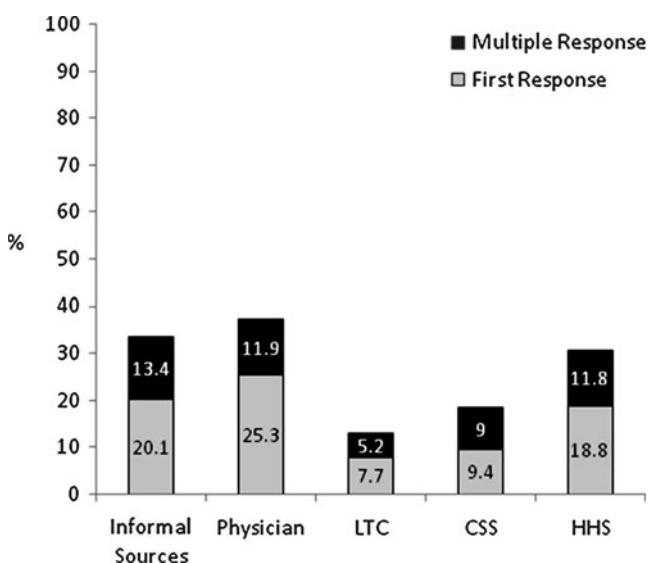
conducted to compare each variable between caregiver and non-caregiver groups. There were no statistically significant differences between caregivers and non-caregivers on the variables of sex, country of birth, language, and marital status (see Table 3). However, caregivers were younger, had higher education and income levels, better self-rated health, more information

sources, and were less likely to have functional limitations than non-caregivers.

Most caregivers (54%) provided care to one person, while 46 per cent provided care to two or more persons. For the first care recipient mentioned, the care recipient was most likely to be a parent (46%) or friend (31%). Most of the first care recipients (88%) described by the caregivers had a physical or mental condition or a health problem that reduced the amount or kind of activity they could perform. Most caregivers provided care daily (26%) or at least once per week (45%).

### *Services and Supports Identified by Participants*

Across all three vignettes, the percentage of participants who identified each type of community health and support service as a source of assistance in a situation of parental dementia is illustrated in Figure 1. The bottom part of each bar illustrates the percentage of respondents by first response, and the top part of each bar illustrates the percentage of respondents who mentioned a specific care source after prompting. When faced with a situation of parental dementia, the highest percentage of participants identified a physician and the physician's office staff as sources of support. This source was named by 25 per cent of the respondents as their first choice, and overall (i.e., multiple response) by 37 per cent of respondents. This response was closely followed by those who mentioned informal sources (20% first response, 34% overall) and home health services (19% first response, 31% overall). Only nine per cent of participants mentioned a CSS as their first choice (18% overall), and eight per cent mentioned long-term care as their first choice (13% overall).



**Figure 1: Percentage of respondents stating where they would turn for help by first and multiple responses.**

### *Factors Associated with Identification of Sources of Help*

Next, we turn to the socio-demographic and other factors that may be associated with the choice of support service. Here we focus on the overall response, that is, when participants mentioned a home health or CSS at any point in their answer, either as their first response or in response to the prompt "Anything else?". Table 4 presents the odds ratios and 95 per cent confidence intervals for each variable by type of community health or support service: (a) informal sources, (b) physician, (c) long-term care, (d) CSSs, and (e) home health services.

Findings from the logistic regressions showed the following explanatory variables not to be statistically significantly associated with any type of community health or support service: country of birth, self-rated health, membership in clubs or organizations, being a caregiver, and having any functional limitations in or outside the home. In contrast, holding all other explanatory variables within the model constant when faced with a situation of parental dementia, the odds of turning to informal sources such as family, friends, and neighbours decreased significantly with age. Looking at the effects of sex, the odds of identifying their physicians as a source of support increased by 40 per cent if caregivers were female rather than male.

The odds of mentioning their physician as a source of support increased by 250 per cent for those participants with higher levels of education (i.e., community college, trade school, or university) compared to those with less than high school education. Knowing where to obtain information about CSSs increased the likelihood of mentioning physicians and home health services as supports for situations of parental dementia. Married participants had lower odds of identifying informal sources of support for situations of parental dementia, compared to those who were unmarried.

### **Discussion**

Our study results provide insight into where older Canadians would turn for help when faced with a situation of parental dementia and the factors associated with their choice of supports. When older adults were presented with vignettes that described situations of parental dementia, they most frequently indicated they would turn to their physician, informal sources of help such as family and friends, home health services, CSSs, and long-term care services. Many CSSs are specifically targeted to assist older adults and their caregivers, yet only 18 per cent of middle-aged or older adults mentioned these services as sources of help in situations of parental dementia.

**Table 4: Logistic regression: Community health and support services and associations with determinants**

| Variables   | Informal Sources | Physician       | Long-Term Care | Community Support Services | Home Health Services |
|---|------------------|-----------------|----------------|----------------------------|----------------------|
|   | OR (95% CI)      | OR (95% CI)     | OR (95% CI)    | OR (95% CI)                | OR (95% CI)          |
| <b>Age (Years)</b>                                |                  |                 |                |                            |                      |
| 50–60 (ref)                                       | 1.0              | 1.0             | 1.0            | 1.0                        | 1.0                  |
| 61–70   | 0.7 (0.5–1.0)    | 0.8 (0.6–1.1)   | 1.3 (0.9–2.0)  | 1.0 (0.7–1.5)              | 1.1 (0.8–1.5)        |
| 71+   | 0.6** (0.4–0.8)  | 0.8 (0.6–1.2)   | 1.2 (0.7–2.0)  | 0.6 (0.4–1.0)              | 1.2 (0.8–1.7)        |
| <b>Gender</b>                                     |                  |                 |                |                            |                      |
| Male (ref)  | 1.0              | 1.0             | 1.0            | 1.0                        | 1.0                  |
| Female  | 1.0 (0.7–1.3)    | 1.4* (1.1–1.9)  | 1.0 (0.7–1.4)  | 1.3 (0.9–1.9)              | 1.4 (1.0–1.8)        |
| <b>Education</b>                                  |                  |                 |                |                            |                      |
| Less than high school (ref)                       | 1.0              | 1.0             | 1.0            | 1.0                        | 1.0                  |
| Some or all high school                           | 1.0 (0.5–1.9)    | 3.0** (1.4–6.5) | 1.0 (0.4–2.6)  | 1.0 (0.4–2.2)              | 0.9 (0.5–1.8)        |
| Community college; non-university; trade          | 0.9 (0.5–1.8)    | 3.6** (1.6–8.2) | 1.5 (0.6–3.7)  | 1.1 (0.5–2.7)              | 1.1 (0.5–2.3)        |
| University or higher                              | 0.9 (0.5–1.7)    | 3.5** (1.6–7.9) | 1.2 (0.5–3.2)  | 1.6 (0.7–3.9)              | 1.4 (0.7–2.7)        |
| <b>Country of Birth</b>                           |                  |                 |                |                            |                      |
| Canadian (ref)                                    | 1.0              | 1.0             | 1.0            | 1.0                        | 1.0                  |
| Foreign born                                      | 1.2 (0.9–1.6)    | 0.9 (0.7–1.2)   | 1.2 (0.8–1.8)  | 0.9 (0.7–1.3)              | 0.9 (0.6–1.2)        |
| <b>Self-Rated Health</b>                          |                  |                 |                |                            |                      |
| Excellent, very good (ref)                        | 1.0              | 1.0             | 1.0            | 1.0                        | 1.0                  |
| Good  | 1.0 (0.7–1.4)    | 0.9 (0.7–1.2)   | 1.4 (0.9–2.1)  | 0.7 (0.5–1.0)              | 1.0 (0.7–1.4)        |
| Fair, poor  | 1.0 (0.7–1.6)    | 0.9 (0.6–1.4)   | 1.0 (0.5–1.7)  | 0.7 (0.4–1.2)              | 0.7 (0.5–1.1)        |
| <b>Membership</b>                                 |                  |                 |                |                            |                      |
| No (ref)  | 1.0              | 1.0             | 1.0            | 1.0                        | 1.0                  |
| Yes   | 0.9 (0.7–1.2)    | 0.9 (0.7–1.2)   | 0.9 (0.6–1.4)  | 1.3 (1.0–1.8)              | 1.3 (1.0–1.7)        |
| <b>Caregiver</b>                                  |                  |                 |                |                            |                      |
| No (ref)  | 1.0              | 1.0             | 1.0            | 1.0                        | 1.0                  |
| Yes   | 0.9 (0.7–1.1)    | 1.1 (0.9–1.5)   | 1.3 (0.9–1.9)  | 1.1 (0.8–1.6)              | 1.3 (1.0–1.8)        |
| <b>Sum of Information Sources†</b>                |                  |                 |                |                            |                      |
| Continuous variable (0–3)                         | 1.2 (1.0–1.3)    | 1.2** (1.1–1.4) | 0.9 (0.8–1.1)  | 1.1 (1.0–1.3)              | 1.3*** (1.2–1.5)     |
| <b>Married</b>                                    |                  |                 |                |                            |                      |
| No (ref)  | 1.0              | 1.0             | 1.0            | 1.0                        | 1.0                  |
| Yes   | 0.7* (0.5–0.9)   | 1.0 (0.7–1.3)   | 1.5 (1.0–2.2)  | 1.0 (0.7–1.4)              | 1.0 (0.8–1.4)        |
| <b>Functional Limitation – In or Outside Home</b> |                  |                 |                |                            |                      |
| No (ref)  | 1.0              | 1.0             | 1.0            | 1.0                        | 1.0                  |
| Yes   | 1.0 (0.8–1.4)    | 1.4 (1.0–1.9)   | 1.1 (0.7–1.6)  | 1.2 (0.8–1.7)              | 0.8 (0.6–1.1)        |
| Chi-Square  | 22.664           | 44.000***       | 13.239         | 38.083***                  | 61.465***            |
| –2 Log Likelihood                                 | 1,399.157        | 1,430.218       | 844.508        | 1,037.466                  | 1,315.740            |
| Cox & Snell R Square                              | 0.020            | 0.039           | 0.012          | 0.034                      | 0.054                |
| Nagelkerke R Square                               | 0.028            | 0.053           | 0.022          | 0.054                      | 0.076                |
| Overall Percentage Correctly Predicted            | 66.3             | 62.5            | 87.1           | 81.2                       | 69.1                 |

\* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$ 

OR = odds ratio

† The OR represents each unit increase in the variable.

The most frequently mentioned CSS was the Alzheimer Society, mentioned by an average of 18 per cent of respondents across the three vignettes and the 10 opportunities to respond. These results are much lower than the 50 per cent to 92 per cent of participants who were aware of selected community health and support services in the study by Strain and Blandford (2002). It is possible that our vignette methodology, by avoiding acquiescence bias, provides

a more accurate estimate of older adults' awareness of CSSs.

The highest percentage of participants (37%) indicated they would turn to their physician for help in situations where a parent has dementia. These results are similar to previous research findings that 40 per cent of adults aged 65 and older spontaneously mentioned the facilitating role played by physicians in accessing

formal, community-based or home health services (Schoenberg, Campbell, & Johnson, 1999). However, other researchers have found that physicians have insufficient information about available services for dementia (Bruce & Paterson, 2000; Fortinsky, 1998) and that they do not refer patients to support services early enough, despite prolonged and often severe caregiver stress (Bruce & Paterson, 2000; Bruce, Paley, Underwood, Roberts, & Steed, 2002). One of the issues is that CSSs for dementia care are not currently integrated within a privately or publicly funded system. For example, accessing home health services or a family doctor does not necessarily provide a link to CSSs for dementia care. Integrated access to such services would likely benefit older adults and their caregivers.

The analysis revealed that few of the socio-demographic and other determinants we assessed were significantly associated with identification of CSSs, home health services, long-term care, physicians, and informal sources as sources of support. The use of physicians as sources of help for situations of parental dementia may be less likely for some groups than others, including men and those with less education. The use of informal sources of help such as family and neighbours may decrease with age. Knowing where to look for information about CSSs was associated with increased likelihood of mentioning physicians and home health services as potential sources of assistance. Further research is needed on the factors associated with identification of dementia care services. For example, Lillie (2008), in using data from this project for her PhD studies, found that people who provide care are much more likely to have knowledge of CSSs than those who do not provide care.

Several factors limit the generalizability of study findings. First, we had a low response rate to the telephone survey, consistent with other studies of access to services (Calsyn & Winter, 2000). The barrage of telemarketing and the use of caller ID and telephone answering services make it difficult to achieve high response rates in telephone interviews. Our sample over-represented older adults who were female, Canadian born, and had high levels of education. As a result, the levels of awareness of community health and support services found in this study are likely inflated, since previous research has shown that women and those with higher education levels have higher levels of service awareness (Calsyn & Roades, 1993; Calsyn, Roades, & Klinkenberg, 1998). Further, we have limited information about the caregivers in this study. For example, we do not know if they were caring for a person with dementia. Although we studied older adults from one city only, limiting our ability to generalize our results, we believe that our findings have wider applicability.

The largest proportion of these older adults indicated they would turn to their physicians and informal supports as sources of help in situations of parental dementia. Research has found that both professionals and informal supports play important mediating roles in linking dementia caregivers to formal services (Cotrell & Engel, 1998). Physicians take on a range of important mediation roles such as ordering services, providing linkages or facilitating connections between services/agencies, advising or recommending services, supplying information on services, and providing reassurance about services (Schoenberg et al., 1999). There is a need to develop and evaluate strategies to help physicians and other health care providers to improve the links between older adults and their caregivers with appropriate CSSs. Such strategies may include educational initiatives, promoting effective inter-professional teamwork and collaboration, and the use of technology such as Internet and email to provide information specific to available community supports for persons with dementia and their caregivers (Cantegreil-Kallen, Turbelin, Angel, Flahault, & Rigaud, 2006; Fortinsky, 2001).

Our study results suggest that efforts should also be made to increase the awareness of older persons and their caregivers related to available services for situations of parental dementia. Harris, Bayer, and Tadd (2002) suggested that older persons may differ in their preferred ways of obtaining information and that multiple approaches should be used including health professionals, organizations providing information and advice, family and friends, leaflets or written documents, television and radio or video, telephone, and the Internet. Some Ontario communities are introducing 211 as a telephone information service, and this may be a promising approach to the lack of awareness ([www.211canada.ca](http://www.211canada.ca)). Particular efforts should be made to address the information needs of immigrant and culturally diverse groups.

In our evolving program of research in this area, we are conducting a study on how primary care physicians and allied health care providers working in their offices help to link older adults to CSSs. We are also writing a paper that examines how useful a social-determinants-of-health model is in predicting knowledge of community health services.

## Conclusion

Lack of awareness of where to turn for help when faced with situations of parental dementia is a serious problem that needs to be addressed so that older adults may continue to live in their own homes using available supports, and so that caregivers avoid unnecessary burden. The lack of awareness of community



support services, in particular, is troubling, given that the very purpose of these services is to help people retain social functioning and quality of life in the community. Action must be taken to improve the ability of physicians and other health care providers to help make these linkages possible.

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